

# Epilepsy in adults

Quality standard

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[www.nice.org.uk/guidance/qs26](http://www.nice.org.uk/guidance/qs26)

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This standard is based on CG137.

This standard should be read in conjunction with QS15, QS27, QS71 and QS101.

## Introduction and overview

This quality standard covers the diagnosis and management of the epilepsies in adults (aged 18 years and older). For more information see the [scope](#) for this quality standard.

### Introduction

Epilepsy is a common neurological disorder characterised by recurring seizures. It is estimated that 320,000 adults in England with a diagnosis of epilepsy are currently receiving anti-epileptic drugs<sup>[1]</sup>. There are more than 40 different types of epilepsy, with 40 different associated seizure types. The nature of epilepsy means that it can be difficult to diagnose accurately. [NICE clinical guideline 137](#) estimates that in 5–30% of people diagnosed with epilepsy the diagnosis is incorrect. A diagnosis of epilepsy can have a wide-ranging impact on a person's health and lifestyle. A key part of this quality standard is therefore focused on improving the diagnosis of epilepsy and ensuring that diagnosis and treatment are confirmed and reviewed as necessary.

For many adults diagnosed with epilepsy the seizures can be controlled through treatment with an anti-epileptic drug or other interventions. Optimal management improves health outcomes and can help to minimise other, often detrimental, impacts on social, educational and employment activity. This quality standard therefore includes a focus on tailoring treatment to the individual circumstances and needs of people with epilepsy so that they are offered the most suitable treatment.

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. They draw on existing guidance, which provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement. The quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following frameworks:

- [NHS Outcomes Framework 2013–14](#) (Department of Health, November 2012)

- Improving outcomes and supporting transparency: Part 1: a [public health outcomes framework for England, 2013–2016](#) (Department of Health, January 2012 and [technical refresh](#) November 2012)
- [The Adult Social Care Outcomes Framework, 2013–14](#) (Department of Health, November 2012)

The table below shows the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving:

The adult social care outcomes framework 2013–14	
Domain 1: Enhancing quality of life for people with care and support needs.	<b>Overarching measure</b> 1A Social care related quality of life <b>Outcome measure</b> <i>People are able to find employment when they want, maintain a family and social life and contribute to the community</i> 1E The proportion of adults with a learning disability in paid employment
NHS outcomes framework 2013–14	
Domain 1: Preventing people from dying prematurely.	<b>Overarching indicator</b> 1a Potential years of life lost (PYLL) from causes considered amenable to healthcare 1ai Adults
Domain 2: Enhancing quality of life for people with long-term conditions.	<b>Overarching indicator</b> 2 Health related quality of life for people with long term conditions <b>Improvement areas</b> <i>Ensuring people feel supported to manage their condition</i> 2.1 Proportion of people feeling supported to manage their condition <i>Improving functional ability in people with long-term conditions</i> 2.2 Employment of people with long-term conditions <i>Reducing times spent in hospital by people with long-term conditions</i> 2.3i Unplanned hospitalisation for chronic ambulatory care sensitive conditions (adults) 2.3ii Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s

Domain 3: Helping people to recover from episodes of ill health or following injury.	<b>Overarching indicator</b> 3a Emergency admissions for acute conditions that should not usually require hospital admission
Domain 4: Ensuring that people have a positive experience of care.	<b>Overarching indicator</b> 4b Patient experience of hospital care <b>Improvement area</b> <i>Improving people's experience of outpatient care</i> 4.1 Patient experience of outpatient services
<b>Public health outcomes framework 2013–16</b>	
Domain 1: Improving the wider determinants of health.	<b>Objective</b> Improvements against wider factors that affect health and wellbeing and health inequalities <b>Indicators</b> 1.8 Employment for those with a long-term health condition including those with a learning disability

## Overview

The quality standard for the epilepsies in adults specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole epilepsy care pathway. An integrated approach to the provision of services is fundamental to the delivery of high-quality care to adults with epilepsy, and the quality standard should be delivered by multidisciplinary teams through a local epilepsy clinical network.

The quality standard should be read in the context of national and local guidelines on training and competencies. All healthcare professionals involved in assessing, caring for and treating adults with epilepsy should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard.

<sup>[1]</sup> [NICE guide for commissioners for the diagnosis and management of the epilepsies in adults, children and young people](#)



## List of quality statements

Statement 1. Adults presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Statement 2. Adults having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.

Statement 3. Adults who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.

Statement 4. Adults with epilepsy have an agreed and comprehensive written epilepsy care plan.

Statement 5. Adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Statement 6. Adults with a history of prolonged or repeated seizures have an agreed written emergency care plan.

Statement 7. Adults who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.

Statement 8. Adults with epilepsy who have medical or lifestyle issues that need review are referred to specialist epilepsy services.

Statement 9. Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

In addition, quality standards that should also be considered when commissioning and providing a high-quality epilepsy service are listed in [related NICE quality standards](#).

# Quality statement 1: Referral to a specialist

## Quality statement

Adults presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

## Rationale

Diagnosing epilepsy can be complex, and it has been estimated that misdiagnosis occurs in 5–30% of people. It is therefore crucial that specialists are involved early in diagnosing epilepsy and that they take great care to establish the correct diagnosis.

## Quality measure

**Structure:** Evidence of local arrangements for adults presenting with a suspected seizure to be seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

**Process:**

a) Proportion of adults presenting with a suspected seizure who are seen by a specialist in the diagnosis and management of the epilepsies.

Numerator – the number of people in the denominator who are seen by a specialist in the diagnosis and management of the epilepsies.

Denominator – the number of adults presenting with a suspected seizure.

b) Proportion of adults presenting with a suspected seizure who are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Numerator – the number of people in the denominator who are seen within 2 weeks of presentation.

Denominator – the number of adults presenting with a suspected seizure seen by a specialist in the diagnosis and management of the epilepsies.

**Outcome:**

- a) Diagnosis of epilepsy that is subsequently found to be incorrect.
- b) Diagnosis of a condition that is subsequently found to be epilepsy.
- c) Number of adults with a recorded seizure type and/or syndrome.

## What the quality statement means for each audience

**Service providers** ensure systems are in place for adults presenting with a suspected seizure to be seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

**Healthcare professionals** ensure that adults presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

**Commissioners** ensure they commission services for adults presenting with a suspected seizure to be seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

**Adults who have a suspected seizure** are seen by a doctor with training and expertise in diagnosing and treating epilepsy within 2 weeks.

## Source guidance

NICE clinical guideline 137 recommendations 1.4.5 (key priority for implementation), 1.4.1 and 1.4.2.

## Data source

**Structure:** Local data collection.

**Process:** a) and b) Local data collection.

**Outcome:** a), b) and c) Local data collection.

## Definitions

A suspected epileptic seizure is a reported acute episode of altered functioning, presumed to be the direct result of a change in electrical activity in the brain, the nature of which raises concerns that a seizure has occurred.

A specialist in the diagnosis and management of the epilepsies is a medical practitioner (a consultant neurologist or consultant with epilepsy expertise), who has epilepsy as a significant part of their workload (at least the equivalent of 1 session a week) with training and continuing education in epilepsy, usually working as part of a specialist epilepsy team.

## Quality statement 2: Investigations

### Quality statement

Adults having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.

### Rationale

The period between the suspected seizure occurring and diagnosis can be a particularly anxious time for patients and families and it is therefore important that investigations are conducted in a timely manner. The earlier a correct diagnosis of epilepsy is made, the sooner tailored therapy can be initiated. Delays caused by a lack of available diagnostic equipment can lead to distress and impact negatively on the everyday lives of patients.

### Quality measure

**Structure:** Evidence of local arrangements for adults having initial investigations for epilepsy to undergo the tests within 4 weeks of them being requested.

**Process:** Proportion of adults having initial investigations for epilepsy who undergo the tests within 4 weeks of them being requested.

**Numerator** – the number of people in the denominator who undergo the tests within 4 weeks of the request.

**Denominator** – the number of adults having initial investigations for epilepsy.

**Outcome:** Patient satisfaction with the length of time between tests being arranged and the tests being performed.

### What the quality statement means for each audience

**Service providers** ensure systems are in place for adults having initial investigations for epilepsy to undergo the tests within 4 weeks of them being requested.

**Healthcare professionals** ensure that adults having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.

**Commissioners** ensure they commission services for adults having initial investigations for epilepsy to undergo the tests within 4 weeks of them being requested.

**Adults having their first tests for epilepsy** have the tests within 4 weeks of them being requested by the doctor.

## Source guidance

NICE clinical guideline 137 recommendations 1.6.3 and 1.6.22.

## Data source

**Structure:** Local data collection.

**Process:** Local data collection.

**Outcome:** Local data collection.

## Definitions

Initial investigations for epilepsy include electroencephalogram (EEG) and magnetic resonance imaging, as appropriate.

Tests such as long-term video or ambulatory EEG, which might be used in the assessment of adults in whom there are difficulties with diagnosis after clinical assessment and standard EEG, might not be possible within this timeframe.

Test results should be interpreted by practitioners who have the necessary competencies.

Information should be provided to adults and families and/or carers as appropriate on the reasons for the tests, their results and meaning, the requirements of specific investigations, and the logistics of obtaining them.

## Equality and diversity considerations

Adults with learning disabilities or challenging behaviour might need particular care and attention to help them tolerate investigations. The same services and investigations should be offered to adults with learning disabilities as are offered to the general population.

# Quality statement 3: Magnetic resonance imaging

## Quality statement

Adults who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.

## Rationale

Magnetic resonance imaging (MRI) is shown by evidence to be the most sensitive and specific neuroimaging option in terms of identifying structural abnormalities in the brain, but access to MRI scanning and reporting facilities varies across the country.

## Quality measure

### Structure:

- a) Evidence of local arrangements for adults who meet the criteria for neuroimaging for epilepsy to have MRI.
- b) Evidence of local arrangements for adults with learning disabilities who meet the criteria for neuroimaging for epilepsy to have MRI.

**Process:** Proportion of adults who meet the criteria for neuroimaging for epilepsy who have MRI.

**Numerator** – the number of people in the denominator who have MRI.

**Denominator** – the number of adults who meet the criteria for neuroimaging for epilepsy.

## What the quality statement means for each audience

**Service providers** ensure systems are in place for adults who meet the criteria for neuroimaging for epilepsy to have MRI.

**Healthcare professionals** ensure that adults who meet the criteria for neuroimaging for epilepsy to have MRI.



Commissioners ensure they commission services for adults who meet the criteria for neuroimaging for epilepsy to have MRI.

Adults who are having neuroimaging (taking pictures of the brain) for epilepsy have magnetic resonance imaging (a type of neuroimaging that uses magnetic fields to produce a picture of the brain; often shortened to MRI).

## Source guidance

NICE clinical guideline 137 recommendation 1.6.20.

## Data source

Structure: a) and b) Local data collection.

Process: Local data collection.

## Definitions

Neuroimaging should be used to identify structural abnormalities that cause certain epilepsies. People diagnosed with idiopathic generalised epilepsy are unlikely to have any aetiologically relevant structural abnormalities and should not therefore undergo neuroimaging.

The criteria for MRI in adults are new-onset epilepsy or failure of first-line medication, unless there is a clear diagnosis of idiopathic generalised epilepsy.

In acute situations computed tomography may be used to determine whether a seizure has been caused by an acute neurological lesion or illness.

## Equality and diversity considerations

The same services, investigations and therapies should be offered to adults with learning disabilities or challenging behaviour as are offered to the general population.

Adults with learning disabilities or challenging behaviour might need particular care and attention to help them tolerate investigations. Reasonable adjustment, such as offering open-bed scanners, sedation or general anaesthesia should be made if necessary to ensure all people who need MRI have access to it.

## Quality statement 4: Epilepsy care plan

### Quality statement

Adults with epilepsy have an agreed and comprehensive written epilepsy care plan.

### Rationale

There are a number of potential lifestyle, health and wellbeing implications directly related to epilepsy. A care plan is an important tool in ensuring that all aspects of a person's life that could be affected by their epilepsy syndrome and the treatment they are receiving are considered and addressed.

### Quality measure

**Structure:** Evidence of local arrangements for adults with epilepsy to have an agreed and comprehensive, written epilepsy care plan.

**Process:**

a) Proportion of adults with epilepsy who have an agreed and comprehensive written epilepsy care plan.

Numerator – the number of people in the denominator who have an agreed and comprehensive written epilepsy care plan.

Denominator – the number of adults with epilepsy.

b) Proportion of adults with an epilepsy care plan who feel they have been involved in developing and agreeing their plan.

Numerator – the number of people in the denominator who feel they have been involved in developing and agreeing their plan.

Denominator – the number of adults with an epilepsy care plan.

**Outcome:** Patient satisfaction with involvement in the epilepsy care planning process.

## What the quality statement means for each audience

**Service providers** ensure that systems are in place for adults with epilepsy to have an agreed and comprehensive written epilepsy care plan.

**Healthcare professionals** ensure that adults with epilepsy have an agreed and comprehensive written epilepsy care plan.

**Commissioners** ensure they commission services for adults with epilepsy to have an agreed and comprehensive written epilepsy care plan.

**Adults with epilepsy** have a written epilepsy care plan that includes details about treatment and any preferences and lifestyle issues and is agreed between them and their healthcare team.

## Source guidance

NICE clinical guideline 137 recommendations 1.3.1 and 1.8.2.

## Data source

**Structure:** Local data collection.

**Process:** a) and b) Local data collection.

**Outcome:** Local data collection.

## Definitions

The comprehensive epilepsy care plan should be a written record of the decisions made about the person's past, present and future care.

It should be discussed and agreed between the adult with epilepsy, their family and/or carers if appropriate and their primary and secondary health and social care professionals. A local template or checklist should be developed to ensure consistency in the content of each epilepsy care plan based on NICE clinical guideline 137 recommendation 1.3.1. The plan should be reviewed on at least annually.

The care plan should include any issues relating to the following topics (as listed in [NICE clinical guideline 137](#) recommendation 1.3.1):

- epilepsy in general
- the person's specific epilepsy syndrome
- diagnosis and treatment options
- medication and side effects
- seizure type(s), triggers and seizure control
- management and self-care
- risk management
- first aid, safety and injury prevention at home and at college or work
- psychological issues
- social security benefits and social services
- insurance issues
- education and healthcare at college
- employment and independent living for adults
- importance of disclosing epilepsy in college or at work, if relevant (if further information or clarification is needed, voluntary organisations should be contacted)
- road safety and driving
- [prognosis](#)
- sudden unexpected death in epilepsy (SUDEP)
- status epilepticus
- lifestyle, leisure and social issues (including recreational drugs, alcohol, sexual activity and sleep deprivation)
- family planning and pregnancy

- voluntary organisations, such as support groups and charitable organisations, and how to contact them.

## Equality and diversity considerations

Consideration should be given to the capacity of someone with epilepsy to be involved in agreeing their epilepsy care plan. Best interest decision making, in accordance with the Mental Capacity Act, should be adhered to.

# Quality statement 5: Epilepsy specialist nurse

## Quality statement

Adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

## Rationale

Epilepsy specialist nurses play a key role in supporting continuity of care between settings for people with epilepsy. There is some evidence that epilepsy specialist nurses improve clinically important outcomes such as knowledge, anxiety and depression for people with epilepsy in secondary and tertiary care.

## Quality measure

**Structure:** Evidence of local arrangements for adults with epilepsy to be seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

**Process:**

a) Proportion of adults with epilepsy who have seen a named epilepsy specialist nurse at diagnosis.

Numerator – the number of adults in the denominator who have seen an epilepsy specialist nurse at diagnosis.

Denominator – the number of adults with epilepsy.

b) Proportion of adults with epilepsy who have seen an epilepsy specialist nurse at their review.

Numerator – the number of people in the denominator who have seen an epilepsy specialist nurse at their review.

Denominator – the number of adults with epilepsy.

c) Proportion of adults with epilepsy who have the contact details of a named epilepsy specialist

nurse.

**Numerator** – the number of adults in the denominator who have the contact details of a named epilepsy specialist nurse.

**Denominator** – the number of adults with epilepsy.

**Outcome:** Patient satisfaction with access to epilepsy specialist nursing.

## What the quality statement means for each audience

**Service providers** ensure that systems are in place for adults with epilepsy to be seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

**Healthcare professionals** ensure that adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

**Commissioners** ensure they commission services for adults with epilepsy to be seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

**Adults with epilepsy** see an epilepsy specialist nurse (a nurse who has training and experience in caring for people with epilepsy) who they can contact between scheduled reviews.

## Source guidance

NICE clinical guideline 137 recommendation 1.8.3.

## Data source

**Structure:** Local data collection.

**Process:** a), b) and c) Local data collection.

**Outcome:** Local data collection.

## Definitions

The role of the epilepsy specialist nurse is described in NICE clinical guideline 137

recommendation 1.8.3 as: to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the adult, and their families or carers where appropriate.

Epilepsy specialist nursing may be provided in a number of different teams, for example the learning disabilities team.

At diagnosis in this context means within 3 months of the epilepsy diagnosis being confirmed.



# Quality statement 6: Prolonged or repeated seizures

## Quality statement

Adults with a history of prolonged or repeated seizures have an agreed written emergency care plan.

## Rationale

An emergency care plan is an important tool in improving the quality of emergency care in the community. It ensures that previous incidents and the agreed treatment strategies are taken into account by healthcare professionals. It also provides guidance for family members or carers who may need to administer emergency treatment. The timely and appropriate management of a prolonged or repeated seizure may significantly reduce the risk of mortality and morbidity (long-term complications) known to be associated with prolonged or repeated seizures.

## Quality measure

**Structure:** Evidence of local arrangements for adults with a history of prolonged or repeated seizures to have an agreed written emergency care plan.

**Process:** Proportion of adults with a history of prolonged or repeated seizures who have an agreed written emergency care plan.

**Numerator** – the number of people in the denominator who have an agreed written emergency care plan.

**Denominator** – the number of adults with a history of prolonged or repeated seizures.

**Outcome:**

- a) Accident and emergency attendances for prolonged or repeated seizures.
- b) Hospital admissions for prolonged or repeated seizures.

c) Patient satisfaction with emergency care for prolonged or repeated seizures.

## What the quality statement means for each audience

**Service providers** ensure systems are in place for adults with a history of prolonged or repeated seizures to have an agreed written emergency care plan.

**Healthcare professionals** ensure that adults with a history of prolonged or repeated seizures have an agreed written emergency care plan.

**Commissioners** ensure they commission services for adults with a history of prolonged or repeated seizures to have an agreed written emergency care plan.

**Adults who have had a prolonged seizure (a seizure that lasted 5 minutes or longer) or repeated seizures (3 or more)** have a written emergency care plan agreed with their healthcare team that sets out how they should be cared for if they have prolonged or repeated seizures again.

## Source guidance

NICE clinical guideline 137 recommendation 1.14.1.4.

## Data source

**Structure:** Local data collection.

**Process:** Local data collection.

**Outcome:**

a) Hospital episode statistics contain the data necessary for the monitoring of accident and emergency attendances.

b) and c) Local data collection.

## Definitions

An agreed written emergency care plan should describe what happens in the event of a prolonged or repeated seizure, including pharmacological treatment that should be given and actions to take,

who to contact and when. It should be agreed between the adult with epilepsy, their family and/or carers if appropriate and their primary and secondary healthcare professionals. Family members and/or carers of adults with epilepsy will need training in order to initiate treatment at home or in the community when necessary. The plan should be reviewed at least annually.

Prolonged seizures are seizures that last 5 minutes or more.

Repeated seizures are seizures that occur 3 times or more within 1 hour.

Any adult with epilepsy who has experienced a prolonged or repeated seizure is considered to have a history of prolonged or repeated seizures.

# Quality statement 7: Referral to tertiary care

## Quality statement

Adults who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.

## Rationale

Tertiary referrals can be vital for a number of reasons such as diagnostic uncertainty, specialised advice on drugs, surgery, epilepsy combined with other complicated medical conditions or psychological problems. Timely and appropriate access to tertiary services remains variable across the country.

## Quality measure

**Structure:** Evidence of local arrangements for adults who meet the criteria for referral to a tertiary care specialist to be seen within 4 weeks of referral.

**Process:** Proportion of adults who meet the criteria for referral to a tertiary care specialist who are seen within 4 weeks of referral.

**Numerator** – the number of people in the denominator who are seen within 4 weeks of referral.

**Denominator** – the number of adults who meet the criteria for referral to a tertiary care specialist.

**Outcome:** Patient satisfaction with referral to a tertiary care specialist.

## What the quality statement means for each audience

**Service providers** ensure systems are in place for adults who meet the criteria for referral to a tertiary care specialist to be seen within 4 weeks of referral.

**Healthcare professionals** ensure that adults who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.

**Commissioners** ensure they commission services for adults who meet the criteria for referral to a tertiary care specialist to be seen within 4 weeks of referral.

**Adultswhomeetthecriteriaforreferraltoateriarycarespecialist** (someone who works as part of a specialist centre with a team of healthcare professionals experienced in assessing epilepsy that is hard to treat or complicated) are seen within 4 weeks of referral.

## Source guidance

NICE clinical guideline 137 recommendation 1.10.2.

## Data source

**Structure:** Local data collection.

**Process:** Local data collection.

**Outcome:** Local data collection.

## Definitions

NICE clinical guideline 137 recommends that referral to tertiary services should be considered when one or more of the following criteria are present:

- The epilepsy is not controlled with medication within 2 years of onset.
- Management is unsuccessful after 2 drugs.
- The adult experiences, or is at risk of, unacceptable side effects from medication.
- There is a unilateral structural lesion.
- There is psychological or psychiatric comorbidity.
- There is diagnostic doubt as to the nature of the seizures or the seizure syndrome.

A tertiary care specialist in epilepsy is an adult or paediatric neurologist who devotes the majority of their working time to epilepsy, is working in a multidisciplinary tertiary referral centre with appropriate diagnostic and therapeutic resources, and is subject to regular peer review.

## Quality statement 8: Re-access to specialist care

### Quality statement

Adults with epilepsy who have medical or lifestyle issues that need review are referred to specialist epilepsy services.

### Rationale

People living with epilepsy may need to seek expert opinion if there are changes in their medical situation or they have lifestyle issues that are affected by their epilepsy or its treatment. It is important that they are able to have timely reviews by specialists to address any issues and receive accurate information to help them make informed choices.

### Quality measure

**Structure:** Evidence of local arrangements for adults with epilepsy who have medical or lifestyle issues that need review to be referred to specialist epilepsy services.

**Process:** Proportion of adults with epilepsy who have medical or lifestyle issues that need review who are referred to specialist epilepsy services.

**Numerator** – the number of people in the denominator who are referred to specialist epilepsy services.

**Denominator** – the number of adults with epilepsy who have medical or lifestyle issues that need review.

### What the quality statement means for each audience

**Service providers** ensure systems are in place for adults with epilepsy who have medical or lifestyle issues that need review to be referred to specialist epilepsy services.

**Healthcare professionals** ensure that adults with epilepsy who have medical or lifestyle issues that need review are referred to specialist epilepsy services.

Commissioners ensure they commission services for adults with epilepsy who have medical or lifestyle issues that need review to be referred to specialist epilepsy services.

Adults with epilepsy who continue to have seizures, have side effects from medication or need specialist advice (for example, for pregnancy) are referred to specialist epilepsy services for a review.

## Source guidance

NICE clinical guideline 137 recommendation 1.20.7 (key priority for implementation).

## Data source

Structure: Local data collection.

Process: Local data collection.

## Definitions

Medical or lifestyle issues that need review by a specialist include:

- diagnostic uncertainty
- pregnancy
- consideration of drug withdrawal
- recurrence of seizures
- side effects of medication.

Any healthcare professional the person with epilepsy sees may determine that they need a specialist review, for example a GP, nurse or hospital doctor.

Specialist epilepsy services include secondary care services, tertiary services and specialist epilepsy nursing, which may be based in the community. The service that is most appropriate to provide the review will depend on the particular medical or lifestyle issue.

# Quality statement 9: Transition from children's to adult services

## Quality statement

Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

## Rationale

The need for continuity of care during transition from paediatric to adult services is particularly important for young people managing the physical and mental transition from adolescence to adulthood. Good management of this transition period by healthcare professionals is vital to develop and maintain the self-esteem and confidence of the adolescent with epilepsy. It also provides an important opportunity to review the diagnosis, classification, cause and management of a young person's epilepsy before they enter adulthood.

## Quality measure

**Structure:** Evidence of local arrangements for young people with epilepsy to have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

**Process:**

Proportion of young people with epilepsy who are being discharged from paediatric epilepsy services who had an agreed transition period between paediatric and adult services.

Numerator – the number of people in the denominator who had an agreed transition period between paediatric and adult services.

Denominator – the number of young people with epilepsy who are no longer being cared for by paediatric services.

**Outcome:** Young people's experience of transition to adult services.



## What the quality statement means for each audience

**Service providers** ensure systems are in place for young people with epilepsy to have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

**Healthcare professionals** ensure young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

**Commissioners** ensure they commission services for young people with epilepsy to have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

**Young people with epilepsy who are changing over from children's to adult health care services** have a period of time when they are supported by both children's and adult services so that the changeover is handled smoothly.

## Source guidance

NICE clinical guideline 137 recommendation 1.17.5.

## Data source

**Structure:** Contained within the Epilepsy12 national audit.

**Process:** a) and b) Local data collection.

**Outcome:** Local data collection.

## Definitions

The purpose of the joint review is to optimise care and treatment for young people with epilepsy and help their move into adult services.

The period of transition should be a joint clinical action between paediatric and adults services, with at least 1 meeting at a joint consultation and a clear action plan for conducting a review after the young person has transferred into adult services.

## Equality and diversity considerations

People with learning disabilities might need a longer transition period to accommodate the additional complexity of their clinical and psychological needs. In addition, people with learning disabilities might remain in paediatric services for longer than those without learning disabilities, depending on their personal preferences, ability to manage their own condition and clinical needs.

## Using the quality standard

It is important that the quality standard is considered alongside current policy and guidance documents listed in the evidence sources section.

NICE has produced a short [support document to help commissioners and others](#) consider the commissioning implications and potential resource impact of this quality standard. A full [guide for commissioners](#) for the diagnosis and management of the epilepsies in adults, children and young people is also available to support the local implementation of NICE guidance and the NICE quality standards for the epilepsies. [Information for the public](#) using the quality standard is also available on the NICE website.

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of healthcare. They are not a new set of targets or mandatory indicators for performance management.

Expected levels of achievement for quality measures are not specified. As quality standards are intended to drive up the quality of care, achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, we recognise that this may not always be appropriate in practice taking account of patient safety, patient choice and clinical judgement, and therefore desired levels of achievement should be defined locally.

We have indicated where national indicators currently exist and measure the quality statement. National indicators include those developed by the Health and Social Care Information Centre through its [Indicators for Quality Improvement Programme](#). For statements for which national quality indicators do not exist, the quality measures should form the basis for audit criteria developed and used locally to improve the quality of healthcare.

For further information, including guidance on using quality measures, please see [what makes up a NICE quality standard?](#)

## Diversity, equality and language

During the development of this quality standard, equality issues have been considered and [equality assessments](#) are published on the NICE website.

Good communication between health and social care professionals and adults with epilepsy is

essential. Treatment and care, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. Adults with epilepsy should have access to an interpreter or advocate if needed.

## Development sources

### Evidence sources

The document below contains clinical guideline recommendations or other recommendations that were used by the Topic Expert Group to develop the quality standard statements and measures.

[The epilepsies](#). NICE clinical guideline 137 (2012; NICE accredited).

### Policy context

It is important that the quality standard is considered alongside current policy documents, including:

Royal College of Physicians and Association of British Neurologists (2011) [Local adult neurology services for the next decade](#).

Department of Health (2006) [Transition: getting it right for young people](#).

Department of Health (2005) [The National Service Framework for long term conditions](#).

Department of Health (2003) [Improving services for people with epilepsy: Department of Health action plan in response to the National Clinical Audit of epilepsy-related death](#).

## Definitions and data sources for the quality measures

References included in the definitions and data sources sections:

[Hospital Episode Statistics](#).

## Related NICE quality standards

- [The epilepsies in children and young people](#). NICE quality standard (2013).
- [Patient experience in adult NHS services](#). NICE quality standard (2012).
- [Medicines optimisation](#). NICE quality standard (referred for development).
- [Managing the transition from children's to adult services](#). NICE quality standard (referred for development).

# The Topic Expert Group and NICE project team

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# Update information

## Minor changes since publication

**December 2016:** Data source updated in statement 9.

**June 2013:** List of Topic Expert Group and NICE project team members added.

**April 2013:** Hyperlinks in Policy context section updated to reflect the Department of Health website move.

## About this quality standard

NICE quality standards are a set of specific, concise statements and associated measures. They set out aspirational, but achievable, markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions. Derived from the best available evidence such as NICE guidance and other evidence sources accredited by NHS Evidence, they are developed independently by NICE, in collaboration with NHS and social care professionals, their partners and service users, and address three dimensions of quality: clinical effectiveness, patient safety and patient experience.

The methods and processes for developing NICE quality standards are described in the [healthcare quality standards process guide](#).

This quality standard has been incorporated into the [NICE pathway for epilepsy](#).

We have produced a [summary for patients and carers](#).

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## Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- [Association of British Neurologists \(ABN\)](#)
- [Epilepsy Action](#)
- [Epilepsy Society](#)
- [Royal College of General Practitioners \(RCGP\)](#)
- [Royal College of Physicians \(RCP\)](#)